



Conceptual Models of Disability and Their Role in the Daily Routine of Clinical Rehabilitation

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Abstract: The aim of this paper is to analyse how the different conceptual models of disability can help daily work of rehabilitation clinicians. Previous papers described the usefulness in rehabilitation psychology of the International classification of Functioning, Disability and Health (ICF) a worldwide-known conceptual model of disability [1-6]. In this paper, we describe how other conceptual models could be useful for rehabilitation clinicians [7-8]. A Narrative review of the literature on conceptual models of disability was undertaken. Based on a previous history of Conceptual models of disability in the 20th century, we describe four groups of models and their impact on rehabilitation: models that analysed the role of pathology, models that analysed the relationship between pathology and its consequences, models that emphasized the role of the environment, and models that analysed the relationship between person and environment. In the daily routine of rehabilitation psychology and in general in rehabilitation sciences, as in the theoretical analysis, one can choose one or another of these options, although the history of the conceptual models of disability shows that the fourth option is the most advanced and the most worldwide-recognized (thanks to the ICF). As for rehabilitation clinicians, the awareness of the chosen option can help in understanding the focus of intervention and to modify it. The main aims of this process is to transform the disablement process into a positive one by which the person can be enabled.

Keywords: Disablement, Enablement, Health, Environment, Individual, Conceptual Models, Dyslexia

1. Introduction

According to the last world report on disability of the World Health Organization, the number of people with disability in the world is about 15%, and it is estimated that about 2,4% of them experience significant difficulties in functioning [9]. Diagnoses are necessary but not sufficient guides to provide health care and socio-medical services, and the study of functioning may better predict outcomes following disease, but the study of the functioning is a very complex one [10-12]. The 20th and the 21st centuries represent a shift in the consequences of disease: from the risk of death related to a pathology to the risk of important consequences in daily life activities, changes in developmental pathways, learning activities, working and

occupational activities and quality of life [5, 7-8, 10, 13]. The main consequence of this shift is the need to create services to support the life of people with functional limitations, and to provide devices, tools of assistive technology and other kinds of assistance. The main purpose of intervention is to increase the quality of life of people with functional limitations and to guarantee them autonomy, independence and possibility to control their own lives [14]. In the organizational stage of the any kind of intervention, the focus could be different, depending on the theoretical choice upon which the clinician chooses to base the intervention. Over the past century there has been an important theoretical analysis about disability. Aiming to analyse this aspects, a narrative review of the literature on conceptual models of disability was undertaken, based on a previous history on conceptual

models of disability and a new literature research. Throughout this century, several authors have sought to define how a person (with an active or no longer active disease) can function better or worse and what variables can mediate the relationship between the person and his/her functioning [7-8, 15] (for a review see Masala and Petretto, 2008 a, 2010). Today, as a consequence of the worldwide diffusion of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization, disability is no longer seen as an attribute of the person nor as a static event, but as a dynamic process that can vary in breadth and severity across the life course and across environments [1, 16-17]. This idea is only a recent one: in Europe and in America, there has been a progressive conceptual development towards it, starting from a vision by which disability was considered an attribute of a person. The analysis of this progressive conceptual development could be the basis for categorizing these conceptual models into four different groups, according to the analysis of the results of the literature research made:

1. Models that consider functional limitation as an attribute of the person with pathology and as a mandatory consequence of pathology (pathology-related models);
2. Models that analyse the role of pathology (and its severity) in the dynamics of disablement (advanced pathology-related models);
3. Models that emphasize the role of the environment in the dynamics of disablement (environment-related models);
4. Models that describe the relationship between the person's characteristics and the environment (relationship between the person's characteristics and the environment-related models).

Taking into account the possibility of some overlapping between different models and the possibility that the same model could share characteristics from two or more groups, in following pages of this narrative review there is the description of these four groups of theoretical analysis about disability, some hint of analysis about the contributions of all these groups to the conceptual model of rehabilitation science and daily activity of rehabilitation clinicians and a discussion about the influences of different conceptual model on intervention in this field. The aim of this analysis is to describe in what way each group of models can guide clinical routine in rehabilitation science.

2. Models

2.1. "Pathology-Related" Models

In the first half of the 20th century but, most of all, after World War I and II, in parallel with the birth of social and health assistance, the need emerged to define eligibility criteria for various forms of social assistance, in order to provide support to those people who had acquired functional disorders from one of the two Wars or due to other pathologies. Indeed, new epidemiological waves concerned pathologies and health in general, with a shift from typically

epidemic pathologies to chronic pathologies and, as a consequence, the shift from the mere risk of death to the risk of important consequences in daily life and autonomy. Although specialists were somewhat interested in the relationship between pathologies and functional consequences, there was probably a common tendency to consider functional limitations as a mandatory consequence of pathology and to see the difficulty to achieve functional independence as an attribute of the person with a pathology. Many clinicians believed that a pathology necessarily implied functional consequences in general, and working consequences in particular, regardless of the severity of the pathology or other variables (e.g. socio-economic status, social network etc.) [18, 7-8]. As a main consequence of this belief, people with pathologies were eligible for social aid and other kinds of assistance related to their pathologies, regardless of their actual functional status. That was probably the positive consequence of this approach; however, no interest was devoted to the process of stigmatization related to it. This approach was adopted by many specialists in the second half of the 20th century and, unfortunately, often also in the following years. The negative consequences of this belief were that people with pathologies were frequently also institutionalized, deprived of their personal freedom and frequently limited in their access to labor market. Various studies in those years described the relationship between pathologies and poverty, probably mediated by the difficulties of pathology-affected people to access the labor market (due to stigma more than to real work impairment) (see for example [19-20]).

2.2. "Advanced Pathology-Related" Models

As an answer to the first previously described belief, at the end of the 1950s and in the 1970s the work of two authors emphasized the importance of distinguishing between different consequences of pathology and to analyze the relationship between pathologies and functional consequences. For the aims of this paper we will describe the work of Saad Nagi, a sociologist of Egyptian origin, who was a consultant for the Institute of Medicine of Washington, and the work of Philippe Wood, an English physician who was a consultant for the World Health Organization [18, 21-23]. Both authors decided to shed light on the role played by some factors in shaping the functioning of a person. Nagi started from a sociological point of view and Wood from a medical point of view but, intriguingly enough, both shared the same point of arrival: the need to understand and define the consequences of disease. Until the work of those authors, having a pathology had been considered synonymous with having functional limitations. Both authors attempted to define the functional consequences of pathologies and to relate them to one another and to the severity of the pathology. For both authors, the quest for semantic clarity was based on the need to understand people's functional profile, to limit deficit and functional limitations and to foster functioning. They described the functional consequences of the pathology, aiming to clarify differences between specific

levels of consequences, and describing the process whereby an individual with a specific active pathology can have functional limitations and disabilities (i.e. limitations in the execution of daily life activities). Though Nagi's work is considered in this paper as an example of the first model group, since the first version of the model, Nagi explicitly acknowledged the role played by the social environment in the disablement process, but these issues became clearer only in the revision of Nagi's model (like the one developed by Verbrugge and Jette in 1994 and the two IOM - Institute of Medicine models developed in 1991 and in 1997) [24-26].

In 1970 the work of Philip Wood soon became the basis for the creation of the International Classification of Impairments, Disabilities and Handicaps (I. C. I. D. H.) [27-28], an international framework aimed at analysing, describing and classifying the consequences of diseases, and distinguishing such consequences as impairments, disabilities or handicaps. The I. C. I. D. H. model sees impairment, disability and handicap as three different levels of pathological consequences, which are related to different levels of experience and of individual awareness [27-28].

Nagi's model also became known thanks to the IOM revisions, and Wood's model became known as the first WHO Disability model. Both models attracted much criticism and soon underwent revision. In 1994, Verbrugge and Jette [24] developed a new model that underlined the role of personal characteristics and environmental demands in the development of the disability process in Nagi's model. Although there are some differences between Nagi's and Wood's models, there are also many converging points, most of all in the description of the relationship between active pathologies and other consequences of disorder, as well as on the need to clarify the semantics of the words to be used in clinical routine. As for negative aspects, both models seem to link consequences of disease directly to disease, not explicitly considering the role of intervening variables (e.g. environmental factors, technologies, social support and so on); moreover, both models emphasize the responsibility of impaired people for their reduced functioning and even for their poor integration into society (this negative consequence mostly affects some interpretations of the WHO model, but perhaps it was not foreseen by the authors). It is noteworthy that Nagi's model refers to environmental factors also in its first version, with a reference to environmental demands.

2.3. "Environment-Related" Models

In the same years and as a consequence of the previously mentioned studies about the relationship between poverty, institutionalization and reduction of personal freedom in people with pathology [19-20], the work of self-advocacy organizations aimed at describing the negative role of the (social and physical) environment in the disability creation process (in Great Britain 'Disabled People's International' (DPI), and in the USA 'Society for Disability Studies' (SDS)). Like UPIAS ('Union of the Physically Impaired Against Segregation'), DPI developed its own disablement model that is now known as the 'social model of disability'. According

to this model and due to a paternalistic approach to pathology and to people with pathologies, some people suffering from functional and structural impairments were deprived of their authority, their freedom and their possibility to choose for their life. Medical and health professionals' decisions influenced all aspects of their lives. In order to limit the negative effects of this paternalistic approach and to promote personal freedom, the authors tried to describe how the physical and social environment can shape difficulties affecting people with functional limitations or impairments and limiting their functional independence. To define that disablement process, they adopted the term 'disabled person' in the sense of being deprived (by the environment) of the capability or of the possibility to perform a specific task. They described disablement as the result of the loss or limitation of the opportunity to participate, because of physical and social barriers [20].

2.4. "Interaction Between the Person and the Environment-Related" Models

Most of these four model groups were developed in the 1990s and are the revision of the models described so far. They are based on the introduction of the role played by the physical and social environment in shaping the disablement process. Nagi himself made a review of his model in 1991, wishing to clarify the role of environmental factors and the individual's characteristics in the disablement process [26]. A major revision process of the I.C.I.D.H. was undertaken, whose result was the ICF [1, 28]. In this model, the role of environmental factors in the dynamics of functioning was described through the so-called "capacity-performance gap": "capacity" is described as the individual's ability to perform a task or an action in a standardized environment (to neutralize the varying impact of different environments on the ability of the individual), while "performance" is defined as what an individual does in his or her current environment (where there can be any kind of positive or negative environmental factors). The gap between capacity and performance is the impact of the environment and it can provide some useful information on what is likely to modify the environment and, thus, improve performance. In that way, the ICF model defines disablement as the result of the interaction between the person and the environment and it focuses on the person, the environment and the relationship between them [3, 10].

Another model has the same focus but probably a clearer description of that relationship: the third revision of Nagi's model made in 1997 by Brandt and Pope of IOM [16]. In their model, they considered whether disablement was an inevitable consequence of pathologies (on the basis of the vicious circle of disablement), or whether this vicious circle could be broken in order to activate a virtuous circle of enablement. The environment was compared to a carpet or mat, the strength or resistance of which is proportionate to the quality and the quantity of the support systems and of the various barriers. The meeting between an individual, who has some potentially disabling conditions, and the environment

may cause stronger or weaker disablement, depending on whether the environment is more or less supportive or upon the presence of many or few barriers. In the mat metaphor, this is represented by how deep the person sinks into the mat. Therefore, given the same impairments and/or functional limitations, there can be different levels of disablement according to the relationship between the individual and the environment. In the metaphor of the mat, each social, psychological or physical factor represents one different layer of the mat, the absence or the lack of which causes the support to become weaker and entails some problems when the individual interacts with the environment [16]. It should be noted that while there are multiple links among the different levels described in the individual dimension (non-disability, pathology, impairment and functional limitation), there are also multiple links between the individual and the environment, therefore the environment can have a positive or a negative influence on each level of the individual. According to this model, disablement is no longer seen as an attribute of the individual, but it is rather a function of the interaction between the individual and the environment, a dependent variable whose value is calculated on the basis of the interaction between the two variables (the individual and the environment) [16].

3. Clinical Routine in Rehabilitation Psychology and Models of Disability

The four groups of models described so far represent four different options in the study of the relationship between pathology and functional consequences. From a theoretical point of view, the aims of the rehabilitation psychology are to increase knowledge about the functioning of people with pathology and, from a clinical point of view, to promote better quality of life, autonomy, independence and functioning of the same people. Within this framework, the choice of one of the four groups of models as described herein could be critical for the intervention implementation. If one chooses the first group of models, it might have the negative consequence of paralyzing any intervention: if it is believed that pathology means functional limitation anyway, then no intervention can be useful! In this situation, only external assistance could be provided with no direct influence on the reduction of functional limitations (for example a non-specific kind of economic aid).

In the second group of models, if one chooses to relate functioning to the presence of pathology, the focus will be on the measurement of functional consequences and on the description of simple consequences (impairment), complex consequences (daily life activities) and consequences at role-level (handicaps or disability). Under these circumstances, the aim of intervention can be the reduction of the pathology, or the reduction of simple and complex functional consequences through the provision of intervening variables which mediate the link between pathologies and their consequences (for example, tools of assistive technology to

reduce impairment or increase independence in daily life activities or specific training modules). According to the third model group, if one chooses to relate functioning to the presence of environmental factors, the focus of intervention will be on the elimination of negative environmental factors and on the creation of positive environmental factors (e.g. removing physical barriers such as steps, providing signals to enhance communication or, at social level, promoting social campaigns aimed at reducing stigma), leaving the pathology unchanged as well as its consequences. Finally, if one chooses to describe functioning as a result of the relationship between a person (with his or her peculiar characteristics) and the environment, the target of intervention will be the creation of virtuous interaction between them and three contemporary foci of intervention will be implemented: on the person, on the environment and on the relationship between them.

As an example, let us consider the use of these four models in the study of the functioning of people with dyslexia, a learning disorders which is very common in school-aged children and in other phases of life (almost 5% or more) [29-31]. As a consequence of using the first group of models, a child with dyslexia is considered unable to read. Any kind of intervention cannot reduce pathology (with so far unknown causes for dyslexia) or functional limitations. These limitations are neither measured nor analysed by clinicians: two different children with dyslexia need the same intervention for the sole fact of being dyslexic, irrespectively of the level of functional limitations. Intervention is often some non-specific economic assistance.

According to the second group of models, the clinician has to measure and define different levels in the functional consequences of dyslexia. A child with dyslexia has a phonologically-based impairment and perhaps other impairments related to the decoding of phoneme-grapheme correspondences, as well as some difficulties in daily life activities related to reading, a handicap likely to make him/her a disadvantaged student, owing to the negative social attitude towards dyslexic students. Two different children can have very different levels of impairment, disability and handicap. After measuring the level of functional limitations, the focus of intervention will be the reduction of the pathology (if possible), or the reduction of impairments, disabilities and handicap. For example, training on grapheme-phoneme correspondences could have the effect of reducing impairment at that level and an intervention on reading could have the effect of reducing difficulties in daily living activities related to reading, such as text comprehension and learning knowledge from reading a text. According to the third group of models, the child is “disabled by the environment “that limits people with dyslexia, due to stigma related to this disorder. The focus of intervention is to promote campaigns with the aim of reducing stigma and promoting a positive vision of dyslexia (for example seeing dyslexia as “a different kind of learning”, or disseminating knowledge about the relationship between dyslexia and creativity or dyslexia and science, as well as information

about the lives of important people with dyslexia, like scientists or painters and so on). In this context, there is no interest either in the peculiar cognitive and neuropsychological profile of the single dyslexic child or in the general characteristics of the disorder. According to the fourth group of models, clinicians analyse the peculiar cognitive and neuropsychological profile of the child, they analyse the (social and physical) environment in which the child lives and learns, they make a list of positive and negative environmental factors, trying to reduce impairments, disabilities, thus increasing positive environmental factors and reducing negative ones. Clinicians try to promote a positive virtuous interaction between the child and the environment. The choice of positive and negative environmental factors is based upon the real peculiar profile of the child, not on general knowledge about dyslexia (for example, for a child with a mainly visual style of learning, a personal reader software for text reading might be not as useful as a visual-based strategy and visual aids for learning).

4. Conclusions and Implications

This paper aimed at describing previous and concurrent conceptual models of disability other than the ICF model, and at explaining their role for rehabilitation science. Even if some models share characteristic from two or more groups, the paper proposed to categorize these models into four groups, according to the focus of interest primarily analysed as the causes of functional limitations in a person. The aim of this analysis was to describe how each group of models could guide the clinical routine of rehabilitation clinicians. The findings can provide information for professional from different fields of rehabilitation about models of disability and their influence in clinical routine. If functioning is related to the presence of a pathology, the focus of intervention could be the reduction of the pathology or the use of intervening variables mediating the link between pathologies and their consequences, leaving the environment unchanged. If functioning is related to the presence of environmental factors, the target of intervention could be the elimination of negative environmental factors and the creation of positive ones, leaving the pathology unchanged as well as its consequences. Finally, if one chooses to describe functioning as a result of the relationship between a person (with his or her peculiar characteristics) and the environment, the target of intervention will be the creation of virtuous interaction between them and three contemporary focuses of intervention will be implemented: on the person, on the environment and on the relationship between them. In the rehabilitation professional's daily routine, as well as in the theoretical reflections about this subject, any of these options can be chosen, although the history of conceptual models of disability used in the past century shows that the fourth option is the most advanced and the most worldwide-recognized (thanks to the ICF) [2,4, 10, 32-34].

There may be several differences in clinical routine concerning the level of analysis of each single model, and

the level of theoretical basis of each intervention: from a surface level to a deeper analysis and integration between the three focuses of interest (person, environment and their relationship). Indeed, a good semantic knowledge in the field of conceptual models of disability and a good awareness of models used in the intervention project development are necessary in specialized fields and also in common-use language, as the use of synonyms could inevitably lead to stigmatization instead of enablement. As for rehabilitation science, the awareness of the chosen option can help understand the focus of intervention and modify it, with the aim of transforming the disablement process into a positive one by means of which the person can be enabled [7-8, 15, 35-37].

To conclude, some strengths and shortcomings of this review should be noted. The choice of the fourth group of models implies a trans-disciplinary approach, rather than involving a group of specialists from different disciplines: it refers to a "rehabilitation clinician" in a general sense. Rehabilitation clinicians should work in such a way to take integrate the study of an high number of disciplines and should study the role of the environmental factors and their mutual relationship with people's functioning. This trans-disciplinary approach and a deeper study of the relationship between people and environment is likely to be the focus of increased research interest in the near future in the rehabilitation sciences.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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